

THE LAURA FLANDERS SHOW

ANITA CAMERON & KEITH JONES ON THE AMERICANS WITH DISABILITIES ACT: A CIVIL RIGHTS MILESTONE WITH MILES TO GO

LAURA FLANDERS: People with disabilities are the largest minority group and the only group any of us can become a member of at any time. In the US alone, about a quarter of all adults have a disability, and of the almost 70 million families here, more than 20 million have at least one disabled family member. 33 years ago, the Americans with Disabilities Act, or ADA, was signed back in 1990, a milestone for civil rights with a promise of inclusion and respect. But three decades on, ableism is alive and well, as you will hear. What's the problem? Anita Cameron and Keith Jones are real life legends in the disability rights and justice movements. Anita has been arrested almost 150 times, putting her precious body on the line for change including back in 1990 when she was part of the Capitol Crawl for passage of the ADA and later in 2017, when she participated in the famous Rotunda takeover with the group ADAPT, fighting proposed cuts to Medicaid. Anita is a writer and a blogger with a long experience in transportation and emergency response. One of her articles appears in successive editions of, "Voices of a People's History of the United States," by the late great historian Howard Zinn. She currently directs minority outreach at Not Dead Yet, which fights against physician-assisted suicide and euthanasia of people with disabilities. Keith Jones's activism was forged in Boston in the 1990s where he worked on healthcare for all and what eventually became the Affordable Care Act or Obamacare. As an African-American activist, entrepreneur and father with cerebral palsy, he's been a strong advocate for independent quality living. He's also out there working for housing, education and voting access for people with disabilities. Jones has been recognized for his leadership by the state of Massachusetts and served on the advisory committee for the redesigned access symbol. He's also the founder of Soul Touchin' Experiences and an Emmy award-winning musician for his work on the soundtrack of, "Rising Phoenix," about the Paralympic games. Like Cameron, Jones's list of accomplishments is long, long, long. The ADA, the Americans with Disabilities Act turns 33 this year. I can't think of two people who've worked harder, smarter longer, or are better placed to share with us their thoughts on progress and blocks to progress at this time. Thank you both. Anita and Keith, it is a joy to have you with us.

KEITH JONES: Happy anniversary. Thank you for having me

ANITA CAMERON: Happy anniversary, ADA, thank you for having me.

LAURA FLANDERS: Let me start with you, Anita. You were active in working for the passage of the Act. What did it change about your life? What did you hope that it would change which is to say what needed changing in the era before?

ANITA CAMERON: Well, I was born with my disabilities and so I was born at a time when disabled kids didn't really have the right to a public education, but I managed to be mainstreamed. When I got into college, you know, I noticed that I needed books, you know, audio books, things of that nature, and there wasn't that. My professors wouldn't allow me to record classes, things of that nature. And so it wound up that I had to leave med school. I was told to find a new career and although I was dejected at first, it led me to ADAPT. And I saw that, you know there was really no public accommodations. I had friends who used wheelchairs who couldn't, you know go to the same places that, you know, I could go. But then, you know, as someone who's blind, there were accommodations that I needed, you know, that we didn't have. I was born too late to participate in the Civil Rights movement, you know, to you know, fight for, you know, Black liberation. And I was born too late and I had a certain guilt about that. So at the age of nine, I made this vow, promise, if you will, that I will work to make the world a better place.

KEITH JONES: I came from St. Louis, Missouri at the end of the sixties in the seventies, and it's very segregated. It was the northernmost, antebellum south state. So my coming into activism was not necessarily like, 'ooh let's be active', it was a matter of necessity solely because if you were a child in the seventies, particularly in certain states, you didn't get a chance. I didn't get mainstreamed until I was 10. So for the first five, six, seven years of my academic career, I was segregated, not only because of my race, but specifically because of my disability. And so those things, tracking through college, high school, employment has led me here. And a lot of these things that we've been active about, healthcare, voting rights, access, are things that really came about because I just wanted to vote. If I want to vote, I can't vote. If I want to just get a job, I can't get a job because the barriers society has placed on the melanin content and the diagnosis has caused intentional barriers to my success. So that's really what led to the activism, although I would rather be on the beach drinking a Mai Tai.

LAURA FLANDERS: Well, as you may know, some of you out there and in our show here, this is personal for me. My father was, his mother had to fight him being kept in so-called crafts schools because of his polio he contracted in his twenties in the war. I think we should do a quick hail to the mothers and the family members and the community people who helped get you out of those segregated workshops. And my grandmother too, after whom I'm named. When the ADA got passed in 1990, a lot of people where I grew up in England looked at it and said, "Oh how fantastic, the US has something now that we wish we had." What was your imagining, your excitement at that moment, Anita, as George H. W. signed that first bill and then a little bit later on it was adapted by his son?

ANITA CAMERON: It is landmark legislation, don't get me wrong but it didn't go far enough in guaranteeing people with disabilities, a civil right to live in the community, rather than being

institutionalized. To remove some of the regulation that people with disabilities have to go through with social security and only have a set amount of assets, it didn't really take into housing and, you know, the other things that we need. And there was a lot that it didn't do.

LAURA FLANDERS: There's a lot of distance between the concept of access and the concept of inclusion, Keith, and this is one of the issues that you've worked on. The ADA, to its credit, used both terms.

KEITH JONES: So the upside of the ADA is that it did move things to the forefront. You know, it's different when you're in the wheelchair and you have to hop the curb versus taking a curb cut or when the doors are 200 pounds and now you can pull them open with a certain amount of pressure. Or when you get to go to a concert, you have line of sight. Or when you're at the hotel you have accessible bedrooms and bathrooms. That is, I mean, so materially speaking, the ADA is again, as you heard before, landmark legislation, but in terms of policy it actually is exactly in line with America. America always walks right, just close enough to say we've done something, we did something but we ain't going to do everything. Like, we'll let you get on the bus, we're not going to make sure you can get off at the next stop.

LAURA FLANDERS: People watching the Supreme Court these days have been bemoaning exactly what you just described, the forward and backward motion towards justice and against discrimination in this country. As you have watched both the decisions coming out of the court around abortion, around voting rights, around discrimination against LGBT people, affirmative action, climate, labor, you name it. What do you see coming to you, Keith first and what do you hear? Because there's been a lot of kind of shock horror. They're taking away our rights, but from the disability community I've heard a more textured response.

KEITH JONES: They like to either say you're disabled or you're woman, you're disabled or you're queer, you're disabled or you're Black. And that's not the case. We are an intricate mosaic of identities. And so watching the Supreme Court decisions come down most recently, us having this conversation, is a bit ironic talking about celebrating landmarks civil rights legislation, when as a person of color, I'm watching, you know my voting rights get gutted under a Black president. As a father, I'm watching my daughter's rights be swept away you know, because people have decided to have a moral high ground who will never give birth. So watching the push and pull, the textured responses, I mean people have been agnostic because like, are you shocked? I'm not clutching my pearls. This is where America has been heading. This is reflexive of the blow back from the progress of the civil rights movement, of the women's movement, of the migrant movement, of education. And so when you get that kind of subset of policy makers, they push this to the Supreme Court and then they say, "Oh, Laura, Anita, we love you but you can't control your body." The irony is, is that that's what disabled people have always heard.

LAURA FLANDERS: Anita, abortion rights have sometimes been cast as a threat to people with disabilities. Is it true? How do you think about it?

ANITA CAMERON: The lives of people with disabilities are so regulated, we don't have true autonomy. Okay. And so I mean, I can guarantee you that the access to healthcare and to reproductive rights and all of that, that we disabled women have to fight for that access anyway. The real danger to people with disabilities now is this doctor assisted suicide, assisted suicide, physician assisted suicide, medical aid, or whatever you want to call it. That is what presents a danger to disabled people and other marginalized communities.

LAURA FLANDERS: Your organization, Not Dead Yet, is currently a plaintiff in a case in California involving what you just mentioned. Why and what's your argument?

ANITA CAMERON: Our argument is that assisted suicide in this case is like I say, in California. So it's referring to California case, but I certainly feel it in a global way, that assisted suicide laws violate the Americans with Disabilities Act because it sets up a two-tiered system. It's inherently discriminatory.

LAURA FLANDERS: For people that aren't familiar with the language of the texts, can you just explain what you mean?

ANITA CAMERON: So assisted suicide is supposed to be for people who are terminal with six months or less to live. Doctors often make mistakes about that. Then what ends up happening is you get your terminal diagnosis. Remember, terminal people are a subset of the disability community, you know what I mean? So people with terminal conditions, who even themselves may not consider themselves disabled are protected under the Americans with Disabilities Act because usually when you're terminal, you know, you are needing help, you know, with three or more activities of daily living. And so they're protected. There was a study in 2021 a Harvard study, a survey if you will, that showed that about 82% of the doctors that they surveyed felt that people with disabilities had a lower quality of life or lesser quality of life than non-disabled people. And so what happens is you combine that with the doctor's biases, disability discrimination, that happens. A doctor's going to be more apt to write you out or maybe even try to convince you that this is a good thing. Because if you're given a terminal diagnosis it's going to be normal to be depressed. And so what do you do? You get mental health treatment, you know. People with disabilities, we already have, you know, limited access to that. And then when you rationalize this, you know, people think, "Oh well it's normal that you would be depressed because of your disability." People, we have this better dead than disabled face.

LAURA FLANDERS: So coming to you, Keith, I mean these questions of bodily autonomy, informed choice, permission, access to information. I mean, it sounds to me as if a lot of values

that are held, good progressive folks think they hold those values but they're missing something in some of their understanding of these issues. Whether it's reproductive rights and justice or these questions around end of life care. How would you have us, in the broader society, change our frame?

KEITH JONES: What we're talking about is how people have, Anita, you used the word rationalized, how people have turned their displeasure of somebody else's existence into codified law. We have this because we have America. America exists on looking at First Nation people saying, "We are going to win the West." We're looking at African, we're looking at descendants of stolen people and saying, "You are property," those things propagate throughout American history. If you're talking about eugenics you're talking about the right to life, the quality of life, you're talking about gynecological care. All of those things came out at the expense of First Nation and African descendants. And so when you get to the part where we're saying, why do I need to convince a doctor who took a hippocratic oath, that my life is worthy of having?

LAURA FLANDERS: Let's talk about climate for a second? I mean, you've got, what is it 18 separate billion dollar weather emergencies so far this year, several hundred people dead. How does disability factor into that? Anita, you're trained as an emergency responder. How does that look to you?

ANITA CAMERON: In disasters, we lose, unfortunately. People with disabilities and, you know, then add on top of that, coming from marginalized communities or communities of color, but people with disabilities and disasters, we are often, so the shelters often won't take us, okay. Even though they're supposed to. Oftentimes we are separated from our family, from our equipment and we wind up institutionalized in nursing homes hundreds of miles away. You know, there really isn't any real uniform standards if you will, out there, to you know, dealing with disability and emergency preparedness or, you know, this situation with the heat, you know. And then remember that often those of us with disabilities, we depend on technology or electronics or whatnot. You look at this heat, one of the duties that I was called to do when I was a CERT in Washington DC, was to staff a cooling center. You know, because we hit 105 degrees.

LAURA FLANDERS: CERTs are Community Emergency Response Teams. Can anyone be in one?

ANITA CAMERON: Yes, yes. Oh yes.

LAURA FLANDERS: And can they join one that teaches them about how to handle the situation better?

ANITA CAMERON: Yes. And you know, I have recruited many people to be CERTs, disabled people. I recruited 30 people in Denver to be CERTs. We had one woman who was 85 years old and blind. She became a successful CERT. We had people with varying, you know, disabilities or for example, here in Rochester, I helped to form this first integrated CERT class that consisted of people with varying disabilities, people who had language barriers, people who were non-disabled. We had 21 people in our class, 19 graduated. We had the big-wigs from DC come. When you include people with disabilities on the ground floor and that includes in your commissions and your committees, on your safety committees and things of that nature, when you include us in that, you know, then that's half the battle because we can tell you the things that we need if you include us in this. How much do you want to bet these places that are sweltering now, how many agencies have consulted people with disabilities and how many climate change folks have thought about the effects of climate change on people with disabilities, particularly in the Global South?

LAURA FLANDERS: One of the things you two have in common is your commitment to cultural change and cultural work. What are you excited about out there?

KEITH JONES: I'm excited because I get to rock out with Anita on a couple of projects. That's one. I'm also excited that we, Tony Hickman and I, who are featured on, "Rising Phoenix," with George Dumont which is the song that won the Emmy just released a new single from my album called, "So Hip Hop." So we're using art, television, because I think what people forget is the point of policy is not for policy's sake, it's for the enjoyment of life. So we're not asking for inclusion just to make it cool. We want to chill and hang out. So I'm excited about the things that I see coming. I'm excited about the young kids that are coming up behind us. Hopefully the world will see that whether we walk, whether we don't, whether we have sensory cognitive disability, that we are just beautiful people. And that's what I hope. That's what I'm excited about.

LAURA FLANDERS: I had the opportunity this weekend to be in Minneapolis and I went to George Floyd Square and George Floyd Square you'll be happy to know, has an all genders bathroom and a wheelchair ramp and they provide water to everyone who goes by. Anita, you too work on the cultural front. You want to tell us a little bit about what you're up to? I know that you were just public about declaring you weren't going to get arrested anymore. That will leave you more time for other things.

ANITA CAMERON: Yes, so I've kind of retired, if you will, from active participation and direct action. But that doesn't mean that I won't have any involvement you know, whether it's behind the scenes or whatever. But there's a big project that I am beginning to work on. I'll startup in earnest in August called, "We were there too," Blacks in Disability History, because the face of disability and disability rights and disability history is white. And we Black folks in particular, our stories are whitewashed, you know, or it's kind of belittled. And so what I want to do is I

want to get those stories of those Black disabled activists who were in the trenches, you know, get them before you know, they, you know, join the ancestors. I have a book coming out called, "Troublemaker." I'm in the process of getting it edited. And so yeah, like Keith, I'm doing a bunch of stuff.

LAURA FLANDERS: It sounds like it. Thank you so much. It's been a pleasure talking with you and onward to the next, I don't know, 33 years of activism. Appreciate your work.

I've heard it said that the human brain gathers information in three ways. One through what we hear, through our ears, recommendations, suggestions, advice from others. Two, what we see, what we read, what we study with our own eyes. Three, what we do, our actual lived experience. That, it turns out, is the deepest sort of knowledge and the sort that actually stands to change our lives. When I think about the ADA, I think it's been around for as long as it took some world religions to get started. A whole lot of us have heard about it. Some may even have read it for ourselves, but what have we actually done to change our lived experience, our real life lives when it comes to respect and inclusion for people with disabilities. Who isn't in our lives on a daily basis, that could be? I'm going to spend some time this summer thinking about that for myself. Who isn't here and why, and what am I missing as a result? You can find my full uncut conversation with these two extraordinary leaders with whom I was very happy to spend a bit of time by subscribing to our podcast. And in the uncut conversation you'll hear their answer to my question about what the story will be that the future tells of now. Are we on the precipice of change? You'll find out. You can get more information at our website. Till the next time stay kind, stay curious. For the, "Laura Flanders Show," I'm Laura. Thanks for joining me.

For more on this episode and other forward thinking content, subscribe to our free newsletter for updates, my commentaries, and our full uncut conversations. We also have a podcast. It's all at lauraflanders.org.